## Status of prevention of parent to child transmission services among HIV-positive mothers from rural South India

Anbarasi Subramaniyan, Sonali Sarkar<sup>1</sup>, Gautam Roy<sup>1</sup>, Subitha Lakshminarayanan<sup>1</sup> Medical Officer, Sathyamangalam CHC, Tamil Nadu, <sup>1</sup>Department of Preventive and Social Medicine, JIPMER, Puducherry, India

## Address for correspondence:

Dr. Sonali Sarkar, Department of Preventive and Social Medicine, JIPMER, Puducherry - 605 006, India. E-mail: sarkarsonaligh@gmail.com

## **Abstract**

**Background:** Tamil Nadu comes under group I high-prevalence state, with <1% prevalence of HIV infection in ante-natal women but above 5% prevalence in high-risk group. One of the ways to control HIV/AIDS in India is through prevention of parent to child transmission (PPTCT), the success of which lies in the utilization of services. **Materials and Methods:** A descriptive qualitative study was conducted to explore the status of utilization of PPTCT services by rural HIV-positive mothers, in the Gingee Block of Villupuram district, Tamil Nadu. All the mothers who tested positive between June 2006 and May 2010 were interviewed in-depth using an interview guide. **Results:** There were 21 HIV-positive mothers during this period, 19 of whom gave consent for the study. Thirteen out of 19 mothers (68%) received Nevirapine prophylaxis, while 15 out of 20 infants born to these mothers (75%) received Nevirapine syrup. During the study period, it was found that 61% of the mothers were not compliant to antiretroviral therapy (ART). **Conclusion:** Poor access to the ART centers was reflected in majority of the cases (79%). There is a pressing need to improve access to quality PPTCT services especially during the intranatal period.

Key words: Adherence, HIV-positive, prevention of parent to child transmission, prophylaxis

## INTRODUCTION

Prevention of new infection in vulnerable population like women and children is one of the prime goals of National AIDS Control Program III. The total number of people living with HIV in India was estimated at 20.9 lakh in 2011, of whom children (<15 years) account for 7% (1.45 lakh) of all infections, and 39% (8.16 lakh) were women. Majority of the HIV infections among children are the result of parent-to-child transmission, and this

can be prevented through an effective package of prevention of parent to child transmission (PPTCT) services integrated with the existing reproductive and child health services. [3] Based on the estimated HIV infections among adult females and assumptions on the effect of HIV on fertility and mother-to-child transmission rates, it is estimated that around 38,000 HIV-positive pregnant women needed PPTCT services in 2011. [2]

A comprehensive PPTCT initiative that emphasizes treatment for HIV-positive women and their children was launched in 2004 by the National AIDS Control Organization (NACO) using funds from the Global Fund to Fight AIDS, Tuberculosis, and Malaria. The PPTCT program involves counseling and testing of pregnant women, detection of HIV-positive pregnant women, and the administration of prophylactic Nevirapine to these women and their infants, to

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prevent the mother-to-child transmission of HIV. Those who are HIV-positive, are given a single dose of Nevirapine prophylaxis at the time of labour and newborn is also given a single dose of Nevirapine within 72 h of birth. [4]

Tamil Nadu comes under group I high-prevalence state, as the prevalence of HIV infection in ante-natal mothers is below 1% but above 5% in high-risk group (HRG). In Tamil Nadu, 22 districts come under group A (1% prevalence in ANC and 5% prevalence in HRG), and 5 districts come under group B (<1% in ANC and 5% in HRG).[4] Tamil Nadu State AIDS Control Society (TANSACS) was established in 1993 to control and prevent the spread of HIV/AIDS. TANSACS was the first AIDS Control Society formed in the country. It provides a comprehensive, low cost PPTCT program of short-term preventive medicine and treatment for the mother as well as the baby by offering safe delivery practice, safe infant feeding practice, counseling and support services. Tamil Nadu's PPTCT program is recognized by NACO as the model program for the entire country, with 10.3 lakh pregnant women covered under the program and 91% of the mother-baby pair were administered Nevirapine in 2009.[5] It is imperative to understand the utilization and accessibility of PPTCT services among the HIV-positive mothers. The objective of this study was to explore the status of PPTCT services by HIV-positive mothers and their children in a rural area of Tamil Nadu.

## MATERIALS AND METHODS

This is a descriptive study of PPTCT services for HIV-infected mothers and their children in the Gingee Block of Tamil Nadu. Gingee is a rural block situated 40 km from Villupuram municipality (district headquarter), 28 km from Tindivanam municipality and 40 km from Thiruvannamalai municipality. All HIV-positive mothers and their children, residing in Gingee Block of Tamil Nadu and detected to be positive between June 2006 and May 2010 were the subjects for this study.

There were 21 HIV-positive mothers who were identified to be HIV-positive during this period. After informed consent, interviews were conducted to collect details on sociodemographic data, compliance and administration of drugs to pregnant women and infants. The compliance and adherence to antiretroviral therapy (ART) and utilization of ART services was recorded during the study period in mothers after having completed their pregnancy and while on routine follow-up at the ART centers. Data on treatment compliance of these subjects were

collected from the registers maintained at ART center in Villupuram. "Adherence to ART" for the purpose of this study meant "missing not >4 doses/month." The lady Out Reach Worker under the district project manager was also involved in data collection. The study protocol was cleared by the Institute Research and Ethics Committees.

## **RESULTS**

In this study, all 21 mothers were identified to be HIV-positive during their ante-natal period. They were registered for ante-natal care, and all mothers were aware of the place and facilities of ART service. All were registered in their ante-natal period (100%), at the time of detection as positive. All of the seropositive pregnant women were married, and 18 subjects (86%) were below 35 years. Most women (71%) had education up to middle school level while four (19%) were illiterate [Table 1]. The monthly per capita income was below Rs. 959 for 76.1% of subjects. Five of the 21 women were housewives and rest were agricultural labourers, mason coolies or housemaids.

In-depth interviews were conducted for 19 women out of 21 mothers as two did not give consent. All mothers received full ante-natal care at the Primary Health Centers (PHCs) and Taluk Hospitals. Identification of institution for delivery was made during the ante-natal period. Those mothers, who were detected as HIV-positive during ante-natal period, were referred to ART center Villupuram. All mothers were counseled by the counselor about the disease progress, availability of ART and measures to reduce the risk of perinatal transmission.

Table 1: Sociodemographic characteristics of HIV positive mothers based on adherence to ART regimen (n=18)\*

Sociodemographic	Utilization of	Nonadherence
characteristics	ART services (%)	to ART (%)
Education		
Illiterate	1 (4.8)	3 (14)
Up to middle school (up to 8 <sup>th</sup> standard)	4 (28.6)	5 (23.8)
Up to high school (9 <sup>th</sup> -10 <sup>th</sup> standard)	3 (14)	2 (9.5)
Socioeconomic status		
Class V	3 (14)	4 (19)
Class IV	5 (23.8)	4 (19)
Class III	-	2 (9.5)
Total	8	10

\*One mother who died within 6 months of delivery excluded. ART=Antiretroviral therapy

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Sixteen (76%) of them were advised to undergo delivery in their area PHCs, whereas 3 of them were referred to a higher institution that is, District Hospital because of their high-risk conditions like breech, short stature and twin pregnancy. In this study, 17 of 19 mothers had vaginal deliveries while 2 underwent caesarian section; 19 mothers delivered 21 infants (two delivered twins). Details of source of care and treatment are mentioned in Figure 1. Thirteen out of the 19 mothers (68%) received Nevirapine prophylaxis. Out of 6 mothers who had not received Nevirapine prophylaxis, five delivered in medical college hospitals (JIPMER, Puducherry and Chingelput Medical College), and one delivered at home. Among 21 infants born to these mothers, one infant was still-born (delivered by breech delivery). Among 20 eligible newborns, 15 (75%) received Nevirapine syrup. All three babies who had not received Nevirapine drops were delivered in medical college hospitals. Status of two newborns were not known [Figure 1].

## Health status of children and HIV-positive mothers

Out of 20 infants born to these 19 mothers, 7 (33%) died before their first birthday. One infant was still-born (delivered by breech delivery). One infant died 1-month after the death of the mother without proper care and feeding, while another infant died due to diarrhea (3 months of life). Twin babies of one subject died within 3 days of delivery, while twin babies of another subject died due to acute respiratory infection and diarrhea (3 and 5 months of life respectively). Twelve children of HIV-positive mothers were examined, and no major diseases were detected among them. All were healthy with normal

milestones. In this study, children were found to be negative for HIV, and so none of them were given ART. All the HIV-positive mothers examined were healthy, while only one mother was found to have a skin infection (fungal), and one had history suggestive of reproductive tract infection. One subject died within 6 months after the delivery.

## Adherence to antiretroviral therapy regimen

Regarding the utilization of ART services, 11 out of 18 mothers (61%) were not compliant to the antiretroviral treatment regimen during the period of the study. The Counselor counseled all mothers at ICTC, about the disease progress. The reasons for nonadherence to ART were explored during the interviews [Figure 2]. Poor access to the ART centers was reflected in majority of the cases (79%) due to lack of transport facilities, travel expenses and long distance to the ART center. Other reasons cited were nonacceptance of HIV result, lack of motivation and stigma to visit the ART center. On further analysis of sociodemographic features of the mothers, it was found that illiteracy or socioeconomic status was not significantly associated with utilization of ART services. Out of 11 subjects who were noncompliant, five subjects preferred availability of ART services in their area PHC itself.

## **DISCUSSION**

During pregnancy, women living with HIV require either ART (antepartum – Azidothymidine AZT from 28 weeks of pregnancy) or ARV prophylaxis for PMTCT (depending on whether they have indications for ART), Cotrimoxazole prophylaxis (if they are eligible), screening for and treatment of TB infection, counseling and care relating to nutrition and psychosocial support. Although mother-to-child transmission accounts for <4% of HIV infections in India, without treatment, these newborns stand

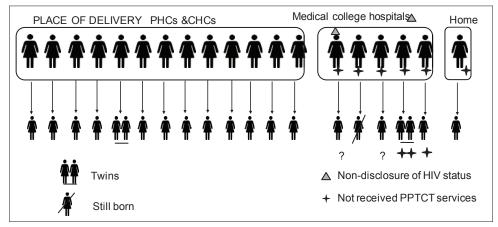


Figure 1: Utilization of prevention of parent to child transmission services in HIV-positive mothers (n = 19) and newborns (n = 21) in the study

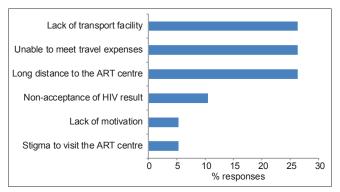


Figure 2: Reasons for nonadherence to antiretroviral therapy (ART) among HIV-positive mothers\* (n = 11)

an estimated 30% chance of becoming infected. [6] The National AIDS Control Program aims to prevent new infection in children from the HIV-positive mothers through PPTCT program and antiretroviral prophylaxis at the time of pregnancy and delivery. Nevirapine tablets and drops are given to mother and baby to prevent perinatal transmission of HIV at the time of delivery and within 72 h after the birth.

In this study, almost all the women were informed about medication to reduce the risk of HIV transmission to their child. In this study, 13 out of 19 mothers (68%) received Nevirapine prophylaxis, while 15 out of 20 infants born to these mothers (75%) received Nevirapine syrup. Nevirapine consumption in this study was lower in comparison with other studies. Assessment of PPTCT services among HIV-positive women across three cities showed that 84% of postpartum women and 86% of their baby received medication.[6] Another study from Tamil Nadu reported that 83% of the pregnant women received Nevirapine prophylaxis, while 96% infants received Nevirapine syrup.[7] Coverage of PPTCT services was found to be high (92%) in both mother and baby in Gujarat.[8] UNGASS study in India showed that PPTCT services varied from 17% to 69% across the country with an average of 50%.[9]

In this study, five mothers and three infants who did not receive Nevirapine prophylaxis delivered in medical college hospitals and tertiary institutions. Though routine screening for HIV is conducted in medical college hospitals during ante-natal care, mothers are not screened for HIV in labor wards. This is because the number of deliveries conducted per day is high. When the mothers approach the hospital in the second stage of labour (referral from peripheral health institutions), their HIV status is not verified. Further, some women prefer such hospitals where their HIV status may not be revealed immediately (for fear of facing discrimination). Fear of discrimination and specific personal experience

with abuse and denial of services led a few mothers to hide their HIV serostatus (or nondisclosure) during the intra natal period. This results in Nevirapine prophylaxis not being given to the mother and child, leading to failure in PPTCT services, and also increased risk to the health staff at these health centers. In a rural tertiary care hospital in West Bengal, Nevirapine dispensing rate of the mothers and the newborns were 30% and 84% respectively. Majority of the pregnant women who came to the labour room directly were deprived of the PPTCT services, similar to findings of this study. [10]

In this study, majority of the HIV-positive mothers were found to be healthy, similar to other studies. <sup>[7]</sup> In this study, seven out of 21 infants born (33%) died before their first-birthday. This is comparable with other studies that the reported rate of death in perinatal infected children is about 30% by the first birthday in India. It was also shown that with or without ART, the child's health can be substantially improved by proper attention to nutrition, hygiene and prompt treatment of common bacterial infections. <sup>[11]</sup> All children in this study were found to be HIV negative, while HIV seropositivity among the tested children was found to be 3.6-14% in other studies. <sup>[7,8]</sup>

In the present study, 61% of mothers were not adherent to ART, which is very high, Level of nonadherence to ART vary from 10% to 33% across the country. At least 95% adherence to ART is required for sustained response in maximal viral suppression.[12] Adherence is a public health concern and is influenced by characteristics of patients like literacy and income. However, in this study, there was no association between these factors and adherence. Poor access to the ART centers was cited in majority of the cases. Out of 11 subjects who were noncompliant, five subjects preferred availability of ART services in their area PHC itself. As the ART center and the link ART center are situated in Head Quarter of the District and Taluk, accessibility is very difficult for them as there is nobody to look after their children, and they also incur loss of daily wages. Other possible reasons for poor access in the study population could be due to lack of perceived need for ART or inadequate counseling, lack of motivation by health functionaries. Logistical barriers to access ART services included lack of transportation and lack of financial resources in some studies.[13] The potential of PPTCT programs to serve as a key entry point in providing treatment and care to HIV-positive women and their families has to be realized and utilized to the maximum potential.

Service gaps in PPTCT program ranges from HIV testing during ante-natal period, posttest counseling, tracking and follow-up of seropositive patients, lack of facilities for institutional delivery, drug unavailability, absence of adequately knowledgeable staff and lack of motivation among the seropositive mothers.[8] Nondisclosure of HIV status by HIV-positive pregnant women due to perceived stigma poses a significant barrier to PPTCT services and could decelerate the progress in control of HIV/AIDS. Avoidance of ART by the women can have long term implications on the control program. Multiple approaches are needed to reduce or eliminate discrimination among health care providers in different levels of health facilities like sub-center, Primary Health Centers, Taluk Hospital, District Hospital and Institutions.[13] Community education strategies play a vital role in the elimination of discrimination and better adoption of PPTCT services by the public.

## **CONCLUSIONS**

Fear of discrimination and specific personal experience with abuse and denial of services led a few mothers to hide their HIV serostatus (or nondisclosure) during the intra natal period. This results in nonprovision of PPTCT services to the subjects. Findings of this research also suggest that accessibility to ART centers makes continuation of ART services a challenging issue. There is a pressing need to improve access to quality PPTCT services for HIV-infected pregnant women in India, during the intranatal period, and improve adherence thereon.

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